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The Development and Testing of a Module on Child Functioning for Identifying Children with Disabilities on Surveys. I: Background

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Abstract

This is the first of three papers that will document the development of a survey module on child functioning developed by UNICEF in collaboration with the Washington Group on Disability Statistics (WG), and demonstrate – both conceptually and through test results – the strengths of that module compared with alternative tools for identifying children with disabilities in household surveys.

This first paper in the series sets the background and reviews the literature leading to the development of the UNICEF/WG Child Functioning Module (CFM) and presents the WG Short Set of questions (WG-SS) and the Ten Question Screening Instrument (TQSI) as precursors, outlining some of their shortcomings and how the UNICEF/WG CFM was designed to meet those challenges.

Subsequent articles will summarize results from the cognitive and field testing of the CFM including comparisons with results derived from the TQSI and the WG-SS.

Keywords

child functioning; disability; TQSI; Washington Group; UNICEF

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[3]See forthcoming article

Background

Adoption and enforcement of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) [1], currently ratified by more than 160 countries, has renewed efforts to mainstream disability on the international agenda. The UNCRPD is a milestone in the promotion and protection of disabled persons' rights: it reaffirms that all persons with disabilities should enjoy every human right and fundamental freedom to effectively participate and be fully included in society on an equal basis with others. Furthermore, the Convention dedicates a specific article to children (art. 7) that outlines the obligation of States to ensure the realization of all rights for children with disabilities, to promote their best interests, and to ensure their right to be heard. Furthermore, the Convention incorporates, within its general principles (art. 3), the respect for the evolving capacities of children with disabilities and their right to preserve their identities.

The Convention also recognizes (art. 31) the importance of data collection on disability, stating that "Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention" and that "States Parties shall assume responsibility for the dissemination of these statistics and ensure their accessibility to persons with disabilities and others". The World Report on Disability also states that "internationally, methodologies for collecting data on people with disabilities need to be developed, tested cross-culturally, and applied consistently" [2, page 267] and that data need to be standardized and internationally comparable for monitoring progress on disability policies, and on the implementation of the UNCRPD across the world. Disability has been explicitly included in the recent post-2015 Sustainable Development Goals, including, in addition to various disability-specific indicators, as a characteristic for disaggregating all personal level indicators.

Disability is a complex and dynamic process that presents considerable challenges for data collection. The first step towards producing good indicators of disability is to have a clear definition that can be operationalized in a quantitative data collection instrument, such as a survey or census. The definition of disability has changed over time and is currently conceptualized as the outcome of the interaction between a person with a functional limitation (difficulties doing basic activities) and an unaccommodating environment resulting in the inability to fully participate in society. In the past, in part due to the complex nature of disability, measures of disability have either been excluded from data collections or have varied widely both across countries and within countries across different instruments. Therefore, it is not surprising that past estimates of disability prevalence have also varied widely, depending upon the approach [3].

When it comes to estimates of childhood disability, across countries prevalence rates range from below one percent to nearly 50 percent depending on the methodology used [4]. Without a high quality, internationally agreed upon measure of childhood disability it is impossible to know if these differences are the result of true differences in the underlying rates of disability or simply an artifact of different methodologies. [1] Moreover, it is not just

[1]For a comprehensive review of past efforts to collect childhood disability data see: [4].

prevalence rates that are affected by the lack of standardization in measurement. Comparisons of outcomes for children with and without disabilities are also affected by how disability is measured.

The lack of data on disability in children is widely acknowledged [2, 5]. This lack stems in large part from conceptual difficulties in defining disability in children, and methodological challenges in the operationalization of the selected definition [6]. Providing reliable data on children with disabilities through population surveys poses complex theoretical, philosophical and technical issues [7].

Even if data collection on childhood disability has generally increased over recent years, these data are still limited and inadequate in terms of description of children with disabilities and how the disabilities affect their lives. This is especially true in low- and middle-income countries [5, 8, 9] where the lack of cultural and language-specific tools for assessment [10] and high cost of administering population-based surveys of childhood disability [11, 12] are common obstacles.

Indeed, several factors undermine the cross-national comparability of the data available on child disability [5, 6, 13, 14, 15]. Disability is defined and conceptualized differently across countries affecting how different cultures count their citizens with disability. Differences in values, or attitudes towards individuals with disabilities, influence not only the type of data being collected (what questions are asked and how questions are framed) and the data collection process but also how individuals will respond to these questions [16].

Cappa et al. [4] provide a comprehensive review of data collection instruments that have been operationalized over the past 190 years from among 716 data sources in 198 countries. A variety of methodologies have been actualized to measure child disability. While some countries use questions specifically developed to assess childhood disability (e.g. MICS [9]), others pose the same questions to children as those used for adults (e.g. American Community Survey [4]). Considering the age of the reference population, some surveys or censuses pose the questions from birth (Tanzania 2008 Household survey [4]) while others from a certain age (Egypt 1999, 2 years and above [4], or MICS [9], 2–9 years). Furthermore, some surveys (e.g. Timor-Leste 2004 Census [4]) adopt a dichotomous answer category, while others use multiple response categories with severity qualifiers (e.g. Serbia 2011 Census [4]). When a severity scale is applied, different types and numbers of items are used and the threshold selected may be different. Therefore, there is a clear need to harmonize child disability measurement in order to produce estimates that are reliable, valid and internationally comparable [5].

The dichotomous approach of asking if a household member “is disabled” or “has a disability” leads to significant underestimates of disability prevalence. Stigma, and the notion that disability refers only to a severe – often only a medically diagnosed – impairment, results in further under-identification of people with disabilities, especially of people with more moderate or less visible difficulties [3]. When the conception of disability is based on the medical model, questions are formulated around impairments or medical diagnoses. Such an approach also tends to under-estimate disability. Lists of diagnoses are

never fully comprehensive and people with less access to health care are less likely to know their diagnosis, which leads not only to underestimates, but biased ones, as well. In addition, research shows that in responding to questions about disability in the household, children and people of lower socioeconomic status are often overlooked, making them even more under-identified [17, 18].

In wealthier countries where services are available, children are often identified as having a disability in educational or medical settings, and then, often by diagnosis. Identification of children with disabilities in poorer countries, where such settings are lacking or not universally available, varies or simply does not occur. Even in the wealthier countries, children with disabilities who lack access to services, or who do not fit into certain diagnostic categories, can also be missed [17, 19].

The bio-psychosocial model of disability approaches the issue differently, looking at the interaction between a person's capabilities and environmental barriers that may limit their participation in society [1, 3, 20]. This is also consistent with the conception of disability recognized by the International Classification of Functioning, Disability, and Health (ICF) [21].

The focus is thus not on what condition a person may have, but rather on what they have difficulty doing -- for example, not asking if a person has cerebral palsy or an amputated leg, but rather asking if the person has difficulty walking. While numerous countries have collected data on children with disabilities over a long period of time, this approach – which is known to produce higher estimates of disability prevalence – is rather recent [20].

Prior to the adoption of the ICF, the Ten Question Screening Instrument (TQSI) was accepted as a standard tool to measure disability among children in low- and middle-income countries [19]. These questions, designed to be answered by mothers in a relatively short amount of time, do not ask about diagnoses or the presence of a "disability", but rather ask whether the child is capable of doing basic activities appropriate to his or her age. In recent years, this tool has been used in many data collection efforts, including as part of UNICEF-supported Multiple Cluster Indicator Survey (MICS) program, the largest source of comparable data on several indicators of child well-being for low- and middle-income countries [9]. While the TQSI was an improvement over previous methodologies, various problems emerged with its continued use as a method for generating population estimates of childhood disability. One problem was that the TQSI was not used as intended. As explained below, the TQSI was designed as a two-stage procedure [9, 22]. The ten questions were designed to cast a relatively large net, and then be followed up by a more extensive clinical assessment in a second stage. The second stage, however, is rarely conducted because it is expensive and logistically complicated. Most surveys using the TQSI only administer the first stage, which tends to generate significant levels of false positives.

In order to address these challenges, the Washington Group on Disability Statistics (WG)[2] and UNICEF have developed a module specifically on child functioning that can be used as

[2]The WG is a United Nations (UN) sponsored City Group comprised of representatives from National Statistical Offices (NSOs) from developing and developed countries, as well as from various UN and other international organizations. The Group was commissioned

a component of national population surveys or as a supplement to surveys on specific topics of interest (for example health or education), to produce comparable data cross-nationally.

Tools for Measuring Child Functioning and Disability

While the concept of disability is the same for children and adults, there are additional considerations for children that warrant development of a set of questions specific to them. Children are in a constant state of development that implies continuous change in their ability to perform actions and activities.

> "In contrast to the relatively stable characteristics of the adult the evolving characteristics of the child represent a moving target, complicating the task of assessing function and distinguishing significant limitations from variations in the normal developmental process" [23, page 67].

Indeed, child development is a dynamic process during which skills emerge in a number of linked domains (sensory-motor, cognitive, communication and social-emotional) requiring that simple skills be mastered before more complex skills can be acquired [24]. Child development experts have identified developmental milestones for each domain, but since children develop and learn to perform basic tasks at different speeds it may be difficult to assess functioning and distinguish between significant limitations and variations in normal development.

Moreover, health and disability measurement for children generally takes place through the filter of a parent or some other adult caregiver. For cost-saving reasons, the use of proxy respondents is a common practice especially in health and disability surveys, as this makes it possible to collect information about persons who may be unable to directly participate in the survey interview due to health conditions or because they are too young. Several studies have been conducted to establish at what age children can self-report their health and the impact on the validity of the findings when parents are acting as proxies for their children [25]. The level of agreement between parent and child depends on the domain and type of information requested; whilst replies are in close agreement in domains related to physical activity and functioning or symptoms, replies in social and emotional domains often differ [26–29].

The Ten Question Screening Instrument (TQSI)

The TQSI was developed as part of the International Pilot Study of Severe Childhood Disability (IPSSCD) in 1984 [30]. The aim was to create a set of questions to identify children with disabilities between 2 and 9 years of age in a manner that could be used in any cultural setting, and thus tied to developmental milestones and not culture-specific skills.

As mentioned above, the TQSI was designed as a first stage screening tool to be followed by a second stage clinical assessment. The questions in the TQSI, to be answered by a child's primary caregiver, focus on the child's ability to undertake age appropriate activities in the

in 2001 by the UN Statistical Commission to improve the quality and international comparability of disability measurement. For more information http://www.washingtongroup-disability.com/

areas of motor/physical functioning, vision, hearing, comprehension/cognition, and speech, in addition to questions on intellectual functioning and seizure disorders (Annex A). Socio-cultural differences within a country and developmental differences among children in the age range 2 to 9 years accounted for, as much as possible, in focusing the respondents' answers to their child's abilities relative to their peers, that is, children of the same age.

Children are considered to have a disability (screen positive) if their parent answers affirmatively to at least one of the ten questions. However, many children who screen positive are found not to have a disability when undergoing the follow-up assessments. In urban Bangladesh, Zaman et al. found that 6.9% of children screened positive for disability using the TQSI alone [31]. A Jamaican study [30] reported that 15.5% of children screened positive using the TQSI, while follow up clinical assessments of those who screened positive found that 3.6% had a severe disability and another 6.7% had moderate disability. False negative rates were low, but about 74% were considered false positives. In the study by Durkin et al. [32], the disability prevalence rate (percent screened positive) using the TQSI alone for children ages 2–9 was 8.2% in Bangladesh, 14.7% in Pakistan and 15.6% in Jamaica. A two-stage study to determine the prevalence of neurological impairment (NI) in Kenya found 9.3% of children (aged 6–9 years) screened positive for disability at stage one, and 6.1% were considered to have moderate or severe NI following the clinical assessment [33]. In another two-stage study in Pakistan [34], results were similar; 20.3% of 649 children 6–10 years of age were screened positive using the TQSI and 6.2% determined to have a disability (mild intellectual disability-ID) upon further assessment. In a more recent study in Bhutan, about 21% of children were identified by the first stage, but only 2.7% were determined to have a significant disability by the follow up assessments [35].

The *sensitivity* of the TQSI was high (ability to correctly identify those with disability: true positives), but not the *specificity* (ability to correctly identify those without disability: true negatives). In other words, the TQSI casts a large net that tends to contain most children with disabilities but also many others without disabilities, known as "false positives." In terms of identifying children for service delivery this is not a problem, since a majority of the false positive children have health conditions or mild difficulties that can benefit from treatment, services or universal design. In fact some of the health conditions identified through the TQSI, such as ear infections, could eventually lead to disability (hearing loss) if untreated. However, the low *positive predictive value* (the proportion of those identified as having disability using the TQSI who, in fact, have a disability) poses a problem for generating a population estimate of the rate of disability; and a second stage of follow-up assessments is required in order to account for the false positives generated by the TQSI. These terms, false positive, false negative, sensitivity, specificity and positive and negative predictive values, are visualized in the table below.

While the developers of the TQSI recommended this two-stage assessment procedure, screening using the TQSI followed by more extensive clinical evaluations, this recommendation is rarely followed. The instrument is described "as a rapid and low-cost method of case finding" [36, page 659] and therefore, results using the TQSI should not be considered as an estimate of the prevalence rate of disability, but rather as a screen for children age 2–9 at higher risk of having a disability than the general childhood population.

Moreover, the TQSI was never cognitively tested and there is no documentation that the questions capture the constructs that are intended – in particular when the instrument is translated into multiple languages.

The TQSI was also used by many low- and middle-income countries as part of three rounds of the MICS, making it the largest source of internationally comparable data on children with disabilities [4]. It should be noted that only the first stage of the TQSI was used without follow-up assessments, except in two countries (Macedonia and Bhutan). Some 50 low and middle-income countries implemented the full first stage of the TQSI in a manner that allows for cross-country comparisons. Disability prevalence in these countries ranged from 3% to 48% with a median of 23%. In the absence of cognitive testing and an assessment of translations into local languages/dialects, it is difficult to interpret results that express such a wide variation in disability prevalence. A lack of understanding of terms used and the subsequent lack of precision in the translation of concepts like “serious delay” (TQSI 1), “fits” (TQSI 6) or “mentally backward” (TQSI 10) may result in unreliable estimates (see Annex A).

Several aspects of the TQSI led to cause for concern in regards to monitoring disability prevalence among children and measuring the impact of disability on children. First, as mentioned above, the TQSI is designed as a screen to catch a broad net of children. The emphasis is on sensitivity and not specificity. This led to overestimates of disability prevalence (including many children with mild or no disability) while subsequently underestimating the impact of disability on children’s lives. The latter occurs when children without disabilities, those who should be in the comparison group, are included in the group of children with disabilities. In other words, the inclusion of those ‘without disability’ in the group ‘with disability’ (false positives), makes the ‘with disability’ more heterogeneous (that is, more like those ‘without disability’) and thus reduces the differences in important outcome measures (like access to education). Second, the TQSI utilizes yes/no responses which tend to identify primarily those with more significant disabilities and it is not possible to distinguish children with mild or moderate levels of difficulty functioning as opposed to those with more severe limitations. Third, the TQSI is meant to be administered only to children under the age of ten, and excludes youths from the ages of 10 to 17. Fourth, some functional domains such as those dealing with psychosocial issues are not included in the battery of TQSI questions. Finally, the wording in some of the questions is outdated, for example, referring to children who are “mentally backward, dull, or slow.”

The UNICEF/WG Child Disability Workgroup

Having completed work on a short set of six questions (WG-SS: adopted in 2006; Annex B) for the general population (designed primarily for censuses and national surveys), and an extended set of questions on functioning for adults (WG-ESF: adopted in 2010), the WG embarked in 2009 on the task of addressing the methodological issues associated with the measurement of disability among children. UNICEF joined the workgroup in 2011 and the two organizations began in earnest to develop a new survey module to identify children and youth with disabilities.

The purpose for disability measurement selected by the WG is the equalization of opportunities for persons with disabilities. Quite apart from screening or surveillance, the methodology adopted by the WG approaches disability measurement by identifying individuals who may have difficulty functioning in universal, basic activity or functioning domains that would subsequently place them at greater risk than the general population of experiencing limited participation in society in a non-accommodating environment. Identifying the at-risk population, those with functional difficulties, would allow for the disaggregation of outcome indicators (like access to education) by disability status and would thereby inform the development and implementation of policies, programs and services that will increase participation for people with disabilities.

The WG realized that while the short set of questions identifies many children with disabilities, they did not adequately address the important functional domains in terms of child development (for example, behavior, learning, coping with change, and psychological functioning) and would result in an underestimation of disability prevalence in childhood. A unique survey module devoted to child functioning was required to improve and expand upon that identification, and to address the perceived shortcomings of the TQSI. As stated earlier, in children, manifestations of disabilities are different by nature, intensity and impact, from those of adults, as are associated activities, participation and the environment in which activities and participation are achieved.

During the course of their work the Child Disability Workgroup (with members from National Statistical Offices from both developed and developing countries) agreed upon a set of guiding principles for the development of the child set:

1. The primary purpose of the questions is to identify children with functional difficulties that may place children at risk of experiencing limited participation in an unaccommodating environment.
2. The questions will provide cross-nationally comparable data. The module is designed to identify children with similar types of functional difficulties in basic, universal activities, regardless of nationality or culture; and the questions reflect basic functional actions that are applicable to children in different countries and life situations.
3. The set of child functioning questions is designed for use as a component of national population surveys or as a supplement to surveys on specific topics; for example, a health or education survey.
4. Disability is understood as a complex process that “denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual (environmental and personal) factors” [21].
5. The ICF [21] is chosen as the conceptual framework and for the selection of relevant domains for the development of current, relevant, and sustainable questions on child functioning.[4]

6. The development of the child functioning questions builds upon the work of the WG-SS and extended set of questions for adults. Findings from several studies and national and international surveys are also taken into account.

7. Consultation with experts, including survey statisticians, paediatricians, developmental psychologists, speech therapists, etc. will be sought to support the work of the WG/UNICEF collaboration.

8. The population reference age for the child functioning questions is 0–17 years. However, capturing disabilities among children under 2 years of age through population surveys is challenging. Due to the transitional nature of the development process for young children, a developmental delay at this age is not necessarily indicative of functional limitations. Therefore, trying to assess difficulties in functioning may yield misleading results for this age group.

9. Questions on child functioning should be asked of parents (preferably mothers) or primary caregivers. Although the use of proxy may introduce some bias as children and parents may have different perceptions of the child's ability, parents/primary caregivers can actually facilitate the assessment of children over a wide age range. Indeed questions for measuring disability addressed directly to children are rare and information provided by children usually supplements information provided by parents or caregivers.

10. For reference, and to focus the respondent on the functioning of their own child in comparison to that child's cohort, where appropriate, questions are prefaced with the statement: "Compared with children of the same age…".

11. Disability is not a yes/no dichotomy, but can be conceptualized on a continuum from minor difficulties in functioning to severe difficulties that may have a major impact on a person's life. Therefore graded answer categories are designed to reflect this continuum. With some exceptions, these are: no difficulty, some difficulty, a lot of difficulty or cannot do at all.

12. The range and the types of functional difficulties – as an expression of disability – are not the same for children and adults. While adults (especially in advancing years) have more difficulty in mobility, sensory, and personal care domains, children more often have difficulties related to intellectual functioning, affect and behaviour.

13. The set of proposed questions will be validated through cognitive and field testing, following established WG procedures.

Early milestones in the development of the UNICEF/WG Child Functioning Module (CFM)

1. **Selection of appropriate and feasible domains of functioning and question design—**Guided by the principles itemized above, questions for the UNICEF/WG CFM

[4]The ICF-CY (ICF-Children and Youth) [37] was designed to respond to the specific and unique aspects of developmental characteristics of children and disability in childhood which were not covered by the ICF itself. The ICF-CY has since been integrated partly into the ICF.

were developed according to a range of domains identified through the ICF and survey questionnaires already in use in several countries. Based on this assessment, an initial set of domains was selected including: seeing, hearing, mobility, communication/comprehension, and learning. In addition to being the most common domains found in existing survey questionnaires, these were also considered to represent activities that were basic (as opposed to complex activities that combine several actions) and universal (common to all cultures and socio-economic groups). However, because child disability comprises a wide range of domains reflecting child development, additional domains of functioning were developed and included: emotions, behaviour, focusing attention/concentrating and coping with change.

In order to operationalized disability according to both the current definition and the intended purpose of the data collection, it was important that question design avoided a medical approach (that focuses on impairments or conditions), and rather embraced the biopsychosocial model. In order to develop the set of questions a review of existing questionnaires that had adopted a functional limitations approach to measuring disability among children was carried out. While survey methodologists contributed expertise in formulating and designing questions, further development of the module relied on comments from subject-matter experts in the field of child development (pediatricians, developmental psychologists, speech therapists etc.), and also evidence resulting from the cognitive tests conducted in several countries [38].

The final questions focused on a particular aspect of the ICF (difficulties doing basic, universal activities) that would identify children at risk of restricted participation in a non-accommodating environment. Where appropriate, questions already tested and adopted by the WG were used, and conformity to established WG question/response design was ensured in order to both harmonize the child functioning questions with existing WG products and to capture the continuum of difficulty.

2. Development of age cohorts and proxy respondents—While recognizing the importance of early detection, it is extremely challenging to capture disability in children under 2 years of age through surveys designed for statistical and research purposes. Among infants and children in this age range, the development process is subjective and developmental norms may be culturally influenced. A perceived developmental delay may not necessarily be a sign of functional limitation. For these reasons the inclusion of children under 2 years of age may lead to large proportions of false positive cases. Therefore it was agreed that the population age reference for the set of child functioning questions is 2–17 years.

Furthermore, questions were developed in a way that would be appropriate for two specific age cohorts: pre-schoolers age 2–4 years and school-aged children 5–17 years. Some domains of functioning are shared by both age cohorts, while others are cohort-specific, in response to the broadly divergent physical and socio-cultural characteristics that distinguish pre-schoolers from school-aged children and youth. For example, the self-care question is not asked of children 2–4 years of age due to normal variation in the ability of young children to perform self-care tasks (feeding and dressing themselves) and the fact that

expectations that may vary significantly by culture. Even when the same domain is covered in both age cohorts, the wording may differ to ensure more accurate measurement based on the age of the child.

Acknowledging the nature and speed of child development, the age ranges 2–4 and 5–17 may seem unaccountably wide. Each domain of functioning, however, either applies to all ages (Does your child have difficulty hearing sounds like people's voices or music?) or, prefaced with the clause: "Compared with children of the same age…", focuses the attention of the proxy respondent on their child and its age cohort. The learning domain in the UNICEF/WG CFM serves as an illustration:

> Compared with children of the same age, does [*name*] have difficulty learning things? Would you say [*name*] has: no difficulty, some difficulty, a lot of difficulty or cannot do at all?

By definition, school-aged children attend school to learn. The span of ages 5 to 17 is as diverse as the attendant school curricula; however, by asking the respondent to make a comparison with children of the same age, the respondent can focus on age-specific learning that mirrors a child's growth and development. In mathematics, for example, learning skills evolve from understanding of whole numbers, fractions, decimals, operations, and measurement in elementary school to more complex operations such as understanding ratios and proportional relationships, expressions and equations, functions, algebra, geometry, statistics and probability, trigonometry and calculus in middle and high school.

Summary

The module on child functioning developed by UNICEF and the Washington Group represents an advance over the TQSI in that it allows for scaled responses to better describe the underlying continuum of disability, and to determine the degree of difficulty – thereby eliminating many potential false positives, while still allowing for the identification of children who may have some difficulties and potentially may be in need of treatment, services or other accommodations. It also addresses a fuller range of functional domains important for child development.

The implementation of the UNICEF/WG CFM will aid in the production of comparable data cross-nationally that, in combination with other data collected on important outcomes (like access to education) can be used to determine the degree to which children with disabilities are able to participate in society on an equal basis with others. These data will support a country's ability to monitor and assess compliance with the UNCRPD and the goals established by the 2030 Agenda for Sustainable Development; and, over time, progress towards the full implementation of the rights of children with disabilities.

Developed with input from a variety of experts and stakeholders to be consistent with the conception of disability underlying the UNCRPD and the ICF, the module has undergone a series of cognitive and field tests that demonstrate that the questions are straightforward to administer and well understood by respondents. Validation of the module and the establishment of its analytic properties will be the subjects of forthcoming articles.

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ANNEX A

The Ten Questions Screening Instrument (TQSI)

1. Compared with other children, did the child have any serious delay in sitting, standing or walking?
2. Compared with other children does the child have difficulty seeing, either in the daytime or at night?
3. Does the child appear to have difficulty hearing?
4. When you tell the child to do something, does he/she seem to understand what you are saying?
5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?
6. Does the child sometimes have fits, become rigid, or lose consciousness?
7. Does the child learn to do things like other children his/her age?
8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognizable words)?
9. For 3 to 9 year olds ask: Is the child's speech in any way different from normal (not clear enough to be understood by people other than his/her immediate family)?

   For 2 year olds ask: Can he/she name at least one object (for example, an animal, a toy, a cup, a spoon)?
10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?

Each question has two response categories:

1. No, no difficulty
2. Yes, some difficulty

ANNEX B

The Washington Group Short Set (WG-SS)

Introduction: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
2. Do you have difficulty hearing, even if using a hearing aid?
3. Do you have difficulty walking or climbing steps?
4. Do you have difficulty remembering or concentrating?
5. Do you have difficulty (with self-care such as) washing all over or dressing?
6. Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question has four response categories, which are read after each question.

1. No, no difficulty
2. Yes, some difficulty
3. Yes, a lot of difficulty
4. Cannot do it at all

Table 1:

Sensitivity, Specificity, Positive Predictive Value, and Negative Predictive Value

		Patients with disability (as confirmed on 2nd stage assessment)		
		Confirmed positive	**Confirmed negative**	
Disability Status: TQSI	TQSI positive	**True positive** (TP) = 20	**False positive** (FP) = 180	Positive predictive value = TP / (TP + FP) = 20 / (20 + 180) = **10%**
	TQSI negative	**False negative** (FN) = 10	**True negative** (TN) = 1820	Negative predictive value = TN / (FN + TN) = 1820 / (10 + 1820) = **99.5%**
		Sensitivity = TP / (TP + FN) = 20 / (20 + 10) = **66.7%**	**Specificity** = TN / (FP + TN) = 1820/(180+1820) = **91%**	